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ABSTRACT

This publication presents examples of research findings that are being put to practice to improve educational services to children with deaf-blindness. Each program description includes photographs and a highlight of key practices. Individual selections are: (1) "Early Intervention: Beginning with Babies" (Deborah Chen), which describes a project in California developing ways for early intervention professionals to help parents; (2) "Assessment: Context Is the Key" (Harvey Mar), which describes a 3-year project on psychoeducational assessment using principles of contextual or ecological frameworks; (3) "Problem Solving for Deaf-Blind Kids: The Approach Is 'Hands-On'" (Charity Rowland and Philip Schweigert), which describes a project in Oregon to develop new approaches to overcoming "learned helplessness" and to improve children's problem-solving skills; (4) "In the School: A Sense of Community" (Michael Giangreco), which describes a Vermont effort to improve parent/professional teams and plan appropriate curriculum; (5) "In the Classroom: Communication and Making Contact" (Lori Goetz), which reports on a California study of ways to foster active learning in deaf-blind children in regular classrooms; (6) "Virtual Reality: A New Way of Seeing" (Dean Inman), which reports on an investigation of computer assisted ways to help these children navigate in their environments; (7)"Communication: Let's Talk Behavior" (V. Mark Durand), which describes an effort in New York to apply principles of behavior assessment to behavior problems in children with deaf-blindness; and (8) "Self-Determination: Charting Your Own Future" (Brian Abery), which describes a Minnesota project on community integration of young people with deaf-blindness. (Contains 62 references.) (DB)

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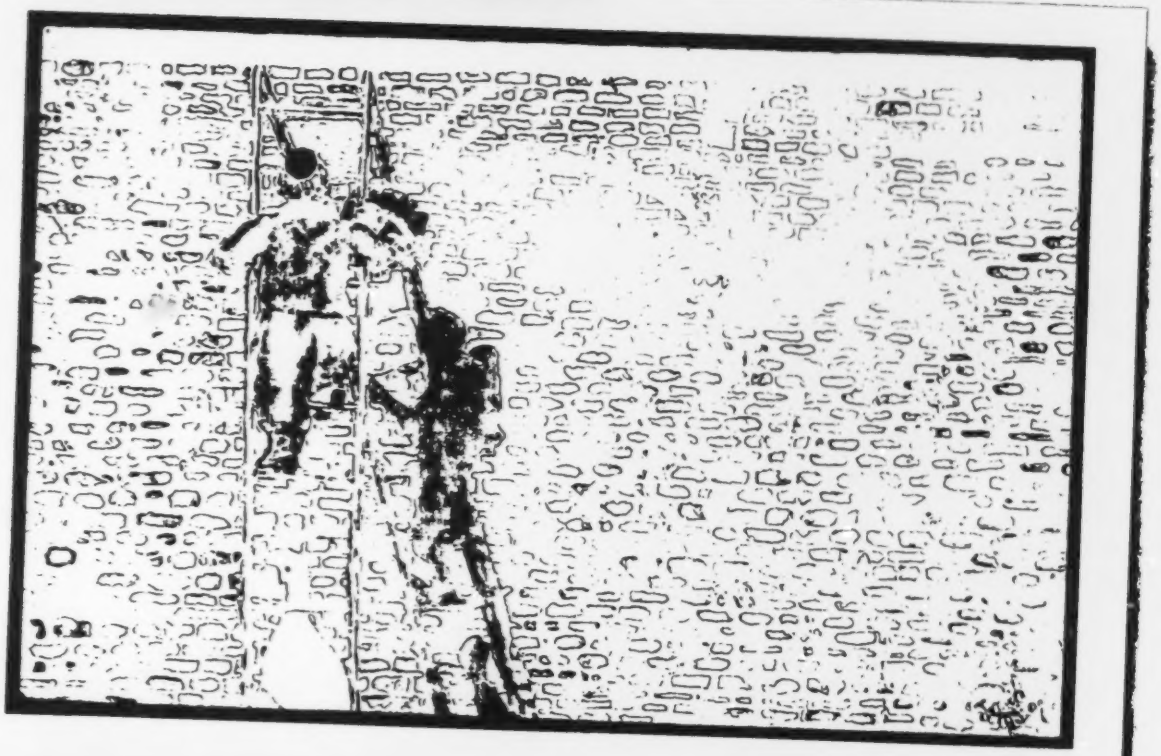
Research to Real Life



"Walls of Ice"
Jared Marcus Diaz
International Helen Keller Art Show
2001

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Innovations *in* Deaf-Blindness

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Welcome to Research to Real Life

In this publication, we give you a glimpse of how current research is making a real difference in the lives of children who are deaf-blind. These children have a combination of hearing and vision losses, and may also have communication, intellectual, and/or physical disabilities. Supporting the education of these children often presents unique challenges to their parents and teachers. For many of these youngsters, the ordinary functions and routines of daily life—playing, exploring, learning, relaxing with one's family—can, at times, be formidable.

Since the 1970s, our federal government has funded many special research-and-demonstration projects to address these challenges, and, over the years, this support has paid off. We now have curricula, teaching tools, training programs, literature, and technology that we could only dream about 25 years ago. In addition, DB-LINK: The National Information Clearinghouse on Children who are Deaf-Blind, was established in 1992 making it possible to further public use of these resources.

The greater challenge, of course, is not generating or collecting these resources, but using them well. The truth is, it often takes years before research findings make their way into the home and classroom. The reasons for this are many, but the bottom line is that parents and teachers may not have access to—or even be aware of—useful resources that promote emerging practices for children who have special needs.

Recent years have seen a unified effort to bridge the gap between research-and-demonstration projects on deaf-blindness and the people who stand to benefit most from their findings. We use the term "research-to-practice" to describe this process. It means researchers working in partnership with parents, teachers, and consumers. It means focusing on problems of everyday life. It means coming up with solutions for the here and now. It means promoting awareness of the rewards of research so that they can be readily shared.
We present eight current special projects to give you a sense of the ongoing accomplishments of this program. These projects address a broad range of topics, but we think that each is a living example of the concept of "research-to-practice," and that their innovations go well beyond the education of children who are deaf-blind. You will hear the voices of a community hard at work to enhance children's social and family lives, and to help them reach their potentials.

Harvey Mar, Ph.D.
April, 2001
New York, NY

For more than 40 years, federal dollars have supported educational programs for children with special needs. Included in this are discretionary grant programs administered by the US Department of Education, Office of Special Education Programs to improve the lives of children who are deaf-blind and their families. Support of research, model demonstration, technical assistance, and other priorities have improved educational outcomes and provided an increasing number of educational opportunities for children with dual sensory impairments. These projects have increased the knowledge base, validated new findings and documented emerging practices

In this publication, DB-LINK presents snapshots of research findings that have meaning and relevance in everyday settings. Through these profiles we hope readers will develop a greater appreciation of the unique needs of children who are deaf-blind, of the Department's efforts to respond to those needs, and examine closely the resources available.

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Early Intervention: Beginning with Babies

It has long been known that eye contact and cooing between parents and newborns is the dance of human bonding. But what if your infant can't see or hear? Research is helping parents lead the way to connecting with their babies.

There's no sure way to prepare for a child who is disabled.

Summer Rae spent the first 27 days of her life in the Infant Special Care Unit of the hospital. Fortunately, her parents were not new to parenting (Summer's brother was 22 months old at the time). However, Virginia, Summer's mother, remembers that those days were filled with almost unbearable worries. Each day, several times a day, she recalls scrubbing her hands for five minutes before she could see her baby. She remembers how she and her husband searched for services, searched for answers to their questions. "At first, I worried about whether or not she was blind," she says. Later, she worried about hearing problems, isolation from society, being labeled. Today, Summer's diagnosis includes cerebral palsy, epilepsy, cortical vision impairment, hearing impairment and severe retardation.

Summer's mother was determined to provide the best possible environment for her child. Through her early intervention program, she was introduced to a project run by Deborah Chen, Ph.D.,a professor in the Department of Special Education at California State at Northridge. Dr. Chen is interested in babies, especially those with disabilities. As part of a four-year project funded by the U.S. Department of Education, she's developed numerous ways for early intervention professionals to help parents.

Key Practices

Early Intervention

Is critical to identifying hearing and vision losses at an early age

Promotes strategies for recognizing and supporting early communication behaviors

Emphasizes preference, routines and turn-taking as important elements in infant communication

By the time an early interventionist enters the picture, parents may be struggling. Their baby who has multiple disabilities may show behaviors that are difficult to interpret. Their child may be passive, fussy, and difficult to engage. The parents may also be grieving because their child is disabled. The easy cooing and clucking games that elicit smiles from other babies seem to have no effect on theirs. They may even feel rejected by their child.

One of the first things an early interventionist can do with parents is to find ways to make the most of their babies' available senses. At first, a parent may feel the child has no responses to anything or is never consistent. But careful observation reveals something else. The parent learns to observe every little movement — a change in muscle tone when a door slams, a vocalization when a soft toy is presented. For many parents it involves slowing down, waiting for the child to process information, have a reaction or express a need.

By doing this, parents are able to discover what the child likes or dislikes. One mother found that her child had a very good sense of smell. She could get him to stop fussing by putting a cinnamon roll near his nose and then giving him a little taste. She learned that when he smelled citrus fruits, he'd throw his head back and cry. Once a parent is able to piece together their child's reactions with what is causing them, communication can begin. Indeed, it has already begun. The bond between parent and child is strengthened. Equally important, the child begins to get in touch with the rest of the world.

Communication is, after all, in its most basic form, action and reaction, back and forth. "Summer hates to have her hair brushed," her mother says. "She bangs her head, fusses and cries." On the other hand, "She loves to be read to (especially Dr. Seuss), and to turn the pages (while tapping for 'more')." Early interventionists teach parents to create opportunities in everyday routines for more back-and-forth interactions.

Repetition is also important. Things that happen everyday should happen in the same way, in the same order. "We let him know what we are going to do with him before we do it," one mother says. "We show him the diaper before we change him." She's learned to use a visual cue. With a child who cannot see, she could use touch.

The video "Making the Most of Early Communication" shows how confusing and distorted the deaf-blind child's world may look. Parents can bring that world into better focus. An early interventionist may suggest putting eye-catching bootees on a baby or using a bright red cup for feeding. Parents can also keep the environment

free of clutter and distractions. They can enhance contrast and improve lighting. They may choose toys that have lights and sounds.

One of the most important things a parent can do is teach a child how to listen and how to watch. This is done best using games and familiar routines. "I would sing to her [in the hospital] and while nursing," Summer's mother says. "And since Day One, I've read to my kids as a bedtime ritual."

In "Making the Most of Early Communication," we see an adult and child play together. As the child pats the tray, the adult responds by banging the tray. We see a game develop from this. An adult may imitate a child's vocalizations, wait for the child's response, and imitate again. These games are more than mere games; they form the basis for communication. They can be used for systematic instruction. Summer's mother can pause in her reading until Summer taps for more. "I praise her," she says, "by saying and touching, 'You said more ' (touch mouth), 'You are listening ' (touch ears). I use textured cards [cards with raised surfaces that Summer can touch] to allow her to choose and anticipate upcoming activities like going outside, food, pool, toys, ride in the car."

"Love and devotion make us do all the work," says a father in one of the videos. "First months were hard, but now we work at it." Another parent states, "Patience is the key word. We give them the answer too soon. Wait. Then, they'll see that we really want to hear what they have to say. We care about what they want." Chen's work emphasizes that it's the parents who know the most about their child and that families are the center of learning for young children. She reminds us, too, that the basic elements of communication and bonding – touch, rhythm, patience and attention – can make the world bigger for us all.

Deborah Chen, Ph. D., California State University at Northridge, Northridge, CA

One of the most important things a parent can do is teach a child how to listen and how to watch. This is done best using games and familiar routines.

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Assessment: Context is the Key

We all remember taking tests in school. The #2 pencils, the big clock, the quiet room punctuated only by the sounds of sighs and pages turning. Tests and evaluations are an essential part of measuring the success of children in school. Results are used to rank students, districts and states, plan programs and formulate curriculums.

For children with disabilities, testing is a far more complex process. In addition to skill levels, evaluations must consider a child's learning style, behaviors, routines and, participation. In fact, for the majority of disabled children, it is the *process* of evaluation, far more than the *results* of the evaluation, that allows teachers and families to plan a meaningful educational program.

Nine-year old Christopher, who is blind and hearing impaired, attends his local public elementary school. In a busy classroom of second graders, he needs to be able to communicate with his teacher and classmates. He doesn't see the posters, charts and books or hear the interactions that motivate the rest of the class. Where will he sit in a busy classroom that will keep him engaged? What activities should occur during the day to increase his communication skills? For children who have the combined disability of deafness and blindness, these are questions that are not usually answered by standard testing techniques. Hearing and vision loss combine

differently for each of these children. They have varying communication styles. There are no standards, no set protocols for evaluating deaf-blind students because there is no one kind of deaf-blind child.

Harvey Mar, a national authority on psychology and child development, has long been interested in how children, especially those with multiple disabilities, understand and acquire information about the world. Mar is the psychology coordinator at St. Joseph's Hospital in Paterson, New Jersey, and assistant professor of Clinical Psychology in Pediatrics at Columbia University in New York City. Many of his ideas are based on the work of Urie Bronfenbrenner, the Cornell University psychologist who first applied the idea of contextual or ecological frameworks to psychological research. Mar's three-year research project, "Psychoeducational Assessment of Students Who Are Deaf-blind" incorporates many of his convictions. Mar has collaborated with Teachers College, Columbia University, and the state deaf-blind projects in Indiana, Maryland, New York and Washington State to gather information about how to assess children with multiple disabilities in their natural settings.

"I've learned to look at the overall goal of testing," he says. "We are looking at a child's intellectual, academic, sensory, social, emotional, behavioral and functional abilities in order to come up with meaningful educational goals. The most effective evaluator will identify strengths as well as needs. He will document the progress the person has made and suggest plans that may help the child grow."

For a child who is deaf-blind, the assessment must take into account the affect vision and hearing loss have on a student's learning style, social behaviors, and communication skills. It should look at his or her ability to perform basic skills at home, in the classroom and on the playground. The report should include important information about how specifics in the environment affect the student, including time of day, location, peer involvement, class structure, and the types of testing materials offered.

According to Mar, an effective assessment "forces evaluators to speculate, to hypothesize what the child can do, within the complexities of the real world." Mar's approach requires evaluators to be

"Contextual assessments show what kids can do, instead of what they can't," Mar says. Instead of looking at how much a child differs from the norm, he tries to discover the child's unique abilities and interests, to discern what makes the child tick.

creative. They must use a potpourri of approaches, a mix of tools. They must be willing to ask questions and test different ideas. Why is it that Christopher is more social, more successful in interacting with his peers on the playground than in the classroom? "Contextual assessments show what kids can do instead of what they can't," Mar says. Instead of looking at how much a child differs from the "norm," he tries to discover the child's unique abilities and interests to discern what makes the child "tick."

How do these evaluations differ from what happens with more "standard" practices? Most children take timed tests along with their classmates in a quiet room following specific directions. For students who are deaf-blind, the process can employ a number of approaches and methods.

Preparation time is important. Before sitting down with the child, evaluators must review the child's history and interview parents, teachers and other service providers. They often study parents' videos of their children and observe the child in typical situations and activities both alone and interacting with others. By doing this, the evaluator gets to know best how to approach and communicate with the student. The child's parents are involved throughout the process of the evaluation. Parents are a valued source of information about their child and their views are included in the statement of educational goals and ways to meet them.

The time, place and methods of the evaluation must be selected carefully. Evaluations of deaf-blind children rarely use standardized tests. Part of Christopher's evaluation took place on the playground during recess. There were additional opportunities for one-to-one sessions and observations during small group activity. The tools and approaches must fit each particular child's needs and abilities.

Writing the final report requires creative thinking – an insightful analysis of available information and observations. It should make recommendations that include how to improve the entire world of the student, including the classroom and social systems.

Although he's evaluated more than 200 deaf-blind children, Mar says that he never feels confident that the evaluation he's done is perfect. "I know I've simply taken samplings of the student's skills, interests, needs and competencies at just one point in time to identify and explore priorities. I focus on the big things, especially communication, which is so important for people with deaf-blindness."

Lisa Picha, a psychologist in the Indianapolis public schools, embraces Mar's approach. "When I'm working with a student, I'm always thinking creatively to identify what she really needs, how to make her curriculum really meaningful and how to foster emerging skills. I do things I need to do, instead of things I had to do (such as IQ tests). I'm also not afraid to interact with the child and find out what she knows. She tells me! And parents are extremely happy. We work as a team instead of as adversaries."

Harvey Mar understands that his contextual approach represents a major change in evaluation techniques, and so he has developed tools to help evaluators, parents, and teachers. A full-length video describes contextual assessment, and a shorter, 12-minute video helps professionals understand parental frustrations with common evaluation techniques and tools. Mar's "Dimensions of Communication: Developing a Profile of Communication Behaviors" provides a practical blueprint for helping evaluators pinpoint a student's present communication skills. Once the skills are identified, teaching strategies can be found to enhance what is already there and move the child to the next level.

Training helps build evaluator confidence. After Mar's training sessions, Picha noted, "I'd be lying to say I wasn't afraid or uncomfortable at first. I had to tell myself to just go in, take a look, ask questions, develop critical questions for that student and evaluate. I really labored over the first report, and I still can't do them easily or quickly. It will take each person a long time to figure it out."

"This [technique] gives you a 'global' picture of the child," says Carolyn Pimentel, a school psychologist at the Indiana School for the Deaf in Indianapolis. "It gives specific ideas that really help teachers build a real, functional vocabulary, read a child's gestures and behaviors, encourage social interaction instead of parallel play; and present highly motivating choices."

Mar and his collaborators have trained hundreds of professionals to use his techniques and to train others. He hopes that, eventually, higher education will incorporate his concepts into teacher-training programs. What began as a three-year research project will then reach and change the lives of people at several educational levels—from children to college students.

Harvey Mar, Ph.D., Columbia University, New York, NY

Key Practices

Assessment should:

- Look at a student across multiple settings, times, and situations
- Provide information about strengths and abilities
- Translate findings into strategies and recommendations that teachers and families can use

Problem Solving: For Deaf-Blind Kids the Approach is "Hands-On"

Deaf-blind children can drive. Will someone please give them the keys?

At first glance, it looks like an average pre-school classroom. There are colorful toys. It's noisy. The kids are busy. At one table, five-year-old Chris is exploring a spoon that his teacher has given him. His eyes widen and his grin broadens as he recognizes its meaning.

"Time to eat," his teacher, Maria Gianotti, confirms. She uses both speech and sign language because Chris cannot clearly see or hear her. He now knows that it's time to find his tray. He wrestles a cracker from the bag and slowly maneuvers his snack into his mouth. For Chris, this represents immense progress.

Before he came to this special education classroom, Chris was used to having things either done "to" him or "for" him. He had no way of knowing what would happen next. He never expressed an interest that anyone understood. Chris had been taught to be helpless. He had needs but no one knew how to interpret them. He had abilities but no one knew how to help him express them. He had stopped trying.

Then Maria Gianotti arrived. Gianotti, an experienced elementary and special education teacher, was participating in a research project at the Oregon Health Science University's Center on Self-Determination. Working with researchers Charity Rowland, Ph.D., and Philip Schweigert, M.Ed., she was helping to test their new approach to overcoming "learned helplessness." Having worked with

Key Practices

Problem solving and independence are fostered by:

- Giving children opportunities to do things for themselves
- Using the objects and routines in everyday environments as opportunities for cognitive development

young children with multiple disabilities for more than 20 years, this duo had already developed breakthrough communication and assessment tools and educational techniques. The question now was how to structure an entire classroom that encouraged Chris to solve problems, do things for himself, make choices and interact with the people and things around him.

Rowland and Schweigert first observed how children deal with everyday routines and looked closely at the skills that were naturally involved. Finding toys, pulling down a towel and opening a cookie jar require skills such as locating, reaching, handling and using. They then developed enjoyable activities that would encourage children to use and expand on those skills at school and at home. Their materials, "Hands-On Problem Solving Skills for Children with Deaf blindness," provide ways to observe what a child is already doing and help parents and teachers see everyday activities as natural opportunities to solve problems.

The approach is very hands-on, emphasizing skills that help children who don't speak or understand speech to solve the everyday problems they face in real life. The tasks are simple – shaking a rattle, turning the pages of a book – but each small task a child accomplishes increases his confidence to tackle a bigger one. "If we think about everyday activities – opening a lunch box or turning on a CD player – as problems to be solved, the opportunities for helping a child to gain skills and confidence are almost limitless," says Schweigert.

Back in the classroom, Gianotti used the School Inventory of Problem Solving Skills (SIPSS), developed by Rowland and Schweigert, to note the skills she observed Chris using as he sought out toys or negotiated the classroom. At home, Chris's parents filled out the equivalent Home Inventory of Problem Solving Skills (HIPSS), listing activities Chris was more likely to do at home, such as petting the dog or turning on the TV. They shared their insights with Gianotti and together they developed new challenges for Chris.

Gianotti noticed how readily the toys that Schweigert brought to the classroom – off-the-shelf playthings selected for skill level as well as for their appeal – harnessed the children's interests. Chris always wanted the vibrating blue-green octopus named "Hip-Hop." It proved to be a lasting reward. The joy of learning something new—something that made him more independent and confident—drew him in. Soon he was searching for the block that fell on the floor and figuring out how to open a milk carton (a surprisingly complex feat). It was a process of mutual discovery: Chris learned to go for it, and Gianotti learned not to do everything for him.

"The kids come in with so many goals and objectives that we want them to accomplish during the year that we work, work, work at," she commented. "We try to set everything up just right. But in reality, sometimes we need to step back and let them take their time and do it themselves." Gianotti was amazed at the results. "I'd spend a lot of my day saying, 'Look! Did you see him open the lid himself?' or 'Did you see him search around for that toy?'" she recalled. Parents shared similar discoveries.

about everyday activities, opening a lunch box or turning on a CD player, as problems to be solved, the opportunities for helping a child to gain skills and confidence are almost limitless.

Independence also involves negotiating the social environment by communicating with others. Building rapport can sometimes be a slow process and involves letting the child know that you're attentive, that you're responsive, and that you're worth talking to. Parents, teachers, specialists and friends must learn to read the slightest sign — a nod, a giggle, a flicker — that shows interest, intent or desire. They must be consistent and patient and respond to the child's lead.

Equally important is building on a child's motivation and helping him or her to more clearly communicate likes and dislikes. This can be as simple as tapping on a certain toy or holding out an empty cup to ask for more milk. Some children who are deaf-blind may learn to use pictures or objects as symbols. "If you get to know a child in the environments they normally function in and pay attention to them," says Rowland, "it's not really a mystical process to find out what they understand and enjoy or don't enjoy doing."

At school, Gianotti made a box for Chris that held items that symbolized school day activities – going to the bathroom, eating, and playing on the swing set. After a while, he learned to find and choose the symbol that represented the activity that he wanted. It didn't take long for Chris to figure out that he was in a good place, where people listened. His desire to interact with others grew. As Chris initiated more and began to use symbols to communicate his wishes, he grew calmer. Gianotti is thrilled with the progress Chris has made and the interest he now shows in his environment.

"No other system pulls theory into practice so well," notes Terry Rafalowski Welch, a consultant who now trains special education teachers. She carries her dog-eared copy of the researchers' tools and their videos to clients across the country. "Other systems can be intimidating; you can feel like you're not doing it 'right'," she explained. "But teachers see that this is logical, affordable, accurate, scientifically sound, brilliantly creative and easy to use. It ripples into the rest of their teaching, such as how they set up their classroom environment and how to present material and supplement it. People feel more competent, and so the children get more of what they need."

Rowland and Schweigert continue to follow up regularly with past project participants, to support them and to revise materials as necessary. And those they've trained, including Gianotti, are training others. The team also plans to apply their materials to children with other disabilities, particularly autism spectrum disorder, and through another grant project plans to continue their work to help young deaf-blind children master their physical and social environments so they become confident, lifelong learners.

Charity Rowland, Ph.D. and Philip Schweigert, M.Ed., Oregon Health Sciences University, Portland, OR

In The School: A Sense of Community

We all know those sayings about the whole being greater than the sum of the parts and two heads being better than one. Probably nowhere does the truth of those sayings become more apparent than when a child's education is planned cooperatively.

Imagine that your daughter Betsy, who is deaf and blind, is about to start fifth grade. What do you want Betsy to learn this year? Identify the continents and major rivers of the world? Stop talking when her mouth is full? Show more courage in gym class? Learn to follow instructions? Find a friend who'll invite her for sleepovers? Discover art? Meet the challenge of fractions? As a parent, your answers will help determine Betsy's curriculum.

Every eligible child who has a disability and attends school has an educational roadmap called an Individualized Education Plan (IEP). Historically, teams of special educators and professionals have plotted this map; coming up with decisions and then sharing them with families. While some parents believed their child was in good hands, others felt outnumbered or overwhelmed. Families felt left out of the process or, when asked for opinions, had little guidance in forming them. Teachers, too, felt that an IEP was at times unwieldy or didn't really have the child at its center.

Michael Giangreco, a research associate professor at the University of Vermont, has worked for more than 20 years in the field of curriculum

LOOK OVER THERE! A WELL-FUNCTIONING TEAM!
ISN'T IT BEAUTIFUL?
© 1990 MICHAEL F. GIANGRECO. ILLUSTRATION BY KEVIN RUELLE
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HERB AND SALLY ADD THE ELUSIVE "COLLABORATIVE TEAM" TO THEIR LIFE LIST OF RARE AND ENDANGERED SPECIES.

It made a much **better** educational program for the **child**... It was just a **very satisfying** way to work because you felt you had a **road map** of where you wanted to be and a **way** to **get there**... and it wasn't someone else's **progress**, it was **Joe's progress** and **you** had a piece in it.

planning for individuals with disabilities. Since 1988, he has worked closely with colleagues Chigee Cloninger, Ruth Dennis and Susan Edelman at the University's Center on Disability and Community Inclusion. Giangreco began to wonder how to most effectively involve parents as team members and how to help teams work productively. Might there be systematic ways to brainstorm and solve problems that would put the child's best interests first? How could team members be assisted to work side-by-side in addressing these interests?

Today, Giangreco's breakthrough approach to curriculum planning, COACH (Choosing Outcomes and Accommodations for Children: A Guide to Educational Planning for Students with Disabilities, 1998) (coauthored with Cloninger and Iverson), gives teams a tool for creating IEPs that address "valued life outcomes." These outcomes include having meaningful relationships, gaining choice and control over the environment, being safe and healthy, having a home, and participating in meaningful activities. Once these outcomes are clarified, the team can use them as a launching pad to develop goals and objectives for an individualized education program.

First, a meeting brings together school staff and families. Parents are asked a series of questions about their child. It becomes clear that they are the real experts—the ones who know the child better than anyone else. Safety and health, for example, may be important for one child who is disabled, whereas another may need friends and a sense of belonging. "What I liked about COACH," one mother says, "was that it gave me a menu of things from which to choose . . . It also helped me learn more about myself and what my priorities were for my child . . ." Throughout the meeting, the child's strengths and needs are shared. As a result, every person at the table is able to get to know the whole child.

"It was no longer a school meeting," says a special educator. "It was a meeting of people who know and care about Emilio." Parents who participate in COACH make other positive comments. "What COACH did more than anything else was made us feel important, that our point of view was acknowledged," one father confides. "[Also] it was structured from more global issues and funneled down to more specific things. They [the valued life outcome questions] opened up a great sense that this was part of an ongoing process." A physical therapist shares: "It made a much better educational program for the child . . . It was just a very satisfying way to work because you felt you had a road map of where you wanted to be and a way to get there . . . and it wasn't someone else's progress, it was Joe's progress and you had a piece in it." As Andrew's father says, "[We] looked at Andrew from a positive perspective. It's more a half-full than half-empty kind of thing . . .Working toward goals rather than working against disabilities."

For several children, using COACH has led to new opportunities and raised expectations, sometimes as basic as riding the school bus with classmates, access to human touch, or active communication with peers. "He went to dances," one parent says. "He went to games. He was just part of it. He was a kid. It was just exciting to see that; things that people generally take for granted."

Once COACH identifies what must be done, a companion process, called VISTA (Vermont Independent Services Team Approach, 1996) helps the team come up with a support services plan. A student who is deaf-blind, attending school in a regular classroom, may work with 10 or more school staff members such as teachers, special educators, paraeducators, speech-language pathologists, orientation and mobility specialists, hearing specialists, vision specialists, social workers, and school psychologists. To complicate matters, in some cases many of the specialists do not stay on the case; for one reason or another, they are replaced by others. Herein lies the next part of the challenge. How do parents and children keep all of these people straight? How can all of the individual skills of team members be channeled into a program that will benefit each student? VISTA addresses these problems.

As one VISTA participant puts it, "People individually look at the hand (occupational therapist), the leg (physical therapist), the mouth (speech-language therapist), and so on, but they seldom have the opportunity to pull all the information together to view the child as a whole." Using VISTA's guidelines, and with the help of a good facilitator, the team members learn about each other's skills and abilities and share ways to work toward a common goal for their students. Says Giangreco, VISTA provides a way for all of the team members to think more creatively and become willing to move beyond the traditional practices.

Giangreco notes that groups using a team decision-making process like VISTA consistently "make different decisions than those made by specialists in isolation." With an emphasis on making the child's support services "only as specialized as necessary," teams can sometimes find ways to involve peers or other school personnel in providing supports within everyday school activities. "It made our team work so much better," says one specialist. "I didn't have to have all the answers," another adds.

Says one occupational therapist, "When parents and teachers can take on more of the responsibilities, with appropriate support, they as well as classmates become more engaged – an added bonus." "Ownership about finding ways to include Heidi shifted from professionals exclusively," her mother said, "to her classmates and peers who used creative problem-solving. [And now] she interacts more with her brother and sister at home."

Cathy Nelson, a deaf-blind specialist and early childhood special educator at the University of Utah in Salt Lake City, says, "After VISTA, our student stayed in the classroom more, had a more cohesive program and the other students took far more responsibility for helping out." Successful relationships and a better program – that's what teamwork is all about.

Michael Giangreco, Ph.D., University of Vermont, Burlington, VT

Key Practices:

FRED EXPRESSES CONCERN AFTER TEAM MEMBERS AGREE TO ALL PULL IN DIFFERENT DIRECTIONS.

In The Classroom: Communication and Making Contact

What defines a quality education? Is it learning to read? Appreciating the arts? Developing problem solving skills? Opinions differ, but most people agree that a child's life should be better for having attended school.

What kinds of educational services do disabled children need to improve their quality of life? Being included in regular school programs is one educational practice that is considered essential by many parents and educators.

A few years ago, one family began to dream that this would be possible for their son. Ben, then three years old, was enrolled in a special education preschool program. In many ways, the program was right for him. Ben is deaf and blind, and developmentally and physically disabled. He wears contact lenses, hearing aids, leg braces, and uses a wheelchair. He communicates by using vocalizations, some sign language, some spoken words, gestures, and body language. Once his health stabilized at age three, his parents hoped that he might eventually attend the neighborhood school where his older sister was already enrolled. The alternative for him was a special school, 10 miles away.

Ben's mother's dream included more than school for her son. The previous Halloween, as she went trick-or-treating with Ben and his older sister, more than one door had rudely closed in their faces. Once her anger and disbelief subsided, she and her husband conjectured that if only other folks knew Ben as they knew him, they would never treat him so cruelly. Thus, her dream of Ben going to the neighborhood school included the chance for others to get to know children who are different.

Children like Ben, who have limited access to visual and auditory information, learn much differently than children who can see and hear. They have trouble anticipating the steps in daily routines, and it may be hard for them to understand social situations and interactions. In order to attend his neighborhood school, Ben's parents knew that Ben would need a support team of educational specialists, and a special education teacher who would work with the regular classroom teacher. Could all these people work together in Ben's best interest? Would the school be able to afford the extra costs of these specialized services? Would school staff need extra training? Would the inclusion of one child open floodgates for others, further stressing the school's resources? These were just some of the issues. Initially, the principal of the school turned down Ben and his family, stating that the school didn't typically take in students with disabilities. Finally, after months of hard work by Ben's family, his current teachers and the Parent-Teacher Organization, Ben was enrolled at his local school.

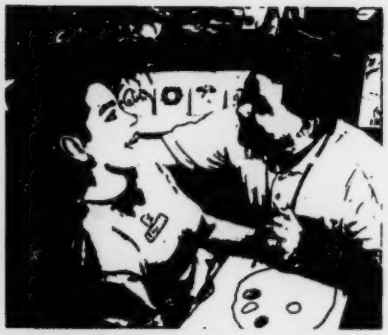
During their struggles to place Ben, his mother met Lori Goetz, a researcher at the California Research Institute at San Francisco State University. Goetz knew research clearly shows that children who are deaf-blind have much to gain from being in general education classrooms. But she also knew that it isn't always easy. The mix of child, teacher, classroom and supports is critical. A child placed in a general education classroom may be technically included, but still isolated from the educational and social activities available to other children. In addition, he or she may not receive a meaningful education. Ben was now part of a learning community, but what would make him a successful learner?

In a project funded by the U.S. Department of Education, Goetz studied ways to foster active learning in deaf-blind children in regular classrooms. She and her colleagues worked with 17 students of different ages and ability levels from suburban, urban, and rural settings. The researchers wanted to give parents, administrators and teachers actual tools for success.

Goetz's research identified certain factors that are essential in order for inclusive education to work. Some were the same issues frequently encountered in developing inclusive programs for any student with disabilities. For example, there is a need for one teacher, usually the special education teacher, to lead in planning and coordinating services. Other findings identified concerns that, while critical for students with deaf-blindness,

students must feel that they belong. Belonging for children with sensory losses depends in large part on their opportunities to

could be applicable across other programs as well. Goetz found that people need ongoing information about the disability through staff training done by persons with specific knowledge about deaf-blindness or through spontaneous modeling. Ben's mother modeled when she took Ben to school functions. His older sister modeled, too. On sharing days, she brought his contact lenses and his braces. She even brought Ben!



Additionally, students must feel that they belong. For children with sensory losses, belonging depends in large part on their ability to communicate. She identified many ways for students to interact with teachers and peers. For example, computer games help children take turns or reach goals together. A simple scrapbook recalls class projects or field trips and prompts active discussions.

What else works? Rearranging a classroom can help the child move around and interact with others more easily. The teacher can watch for communication opportunities and interpret the deaf-blind child's behaviors for others. She can brainstorm with the classmates and peers to find ways to change or deal with certain problems, allow more time for instruction and one-to-one interactions. Teachers have always used creative classroom techniques for dealing with all children, not just those who are deaf-blind. What teacher hasn't moved the easily distracted child to the front of the room or helped classmates understand one child's anger or shyness? What teacher has not searched for ways to bring two children together to make the most of individual strengths?

Key Practices

These strategies are so natural and so easy to employ that they appeal to a teacher who is anxious about incorporating a child with special needs. The strategies can help any child fit in, learn better and feel close to the school community. Goetz's research is expanding now to study the use of social supports with children identified as "at-risk" for dropping out of school.

Goetz's research on inclusive education has also benefited children who have other types of disabilities. She reports that social support strategies (providing information, providing high-and low-tech ways to communicate, facilitating social interactions) are being used by speech-language therapists and teachers of students who are visually impaired. Students without disabilities have used the strategies to make a videotape to introduce a deaf-blind student to students at a new school. Parents have taught first graders about the challenges faced by those who have a vision or hearing loss. Children are learning to accept and value their peers. They are probably teaching their parents to do the same.

Today, Ben is in fifth grade. "He has every reason to get up in the morning," his mother says. "He is very much a part of his school." He participates in camping and hiking adventures with his classmates. He loves to swim. "Ben is growing up with children that will be the community of the future," she continues. "They will know him, welcome him, and value his participation. The children will treat people with disabilities as their fellow community members."

Lori Goetz, Ph.D., San Francisco State University, San Francisco, CA

Virtual Reality: A New Way of Seeing

What do landing the space shuttle and crossing the street have in common?

Virtual reality.

Simulation, a practice once reserved for the frontiers of space travel, is now being used to create a virtual reality that teaches blind children to "see" oncoming traffic.

Kevin, age 21, and Bryan, age 19, are students at the Oregon School for the Blind. They know about crossing streets. "First," Kevin says, "you have to determine what kind of intersection it is, a lighted one or one with stop signs. The ones with stop signs are the hardest to cross. The lighted ones have traffic surges, then silence, then another surge. A little bit of silence tells you when to go."

Kevin and Bryan are both legally blind and go places using white canes. How do they anticipate the car coming around the corner? They are both terrific listeners. They "see" with their ears.

Dr. Dean Inman is a senior scientist with the Applied Computer Simulation Labs at the Oregon Research Institute in Eugene, Oregon. He has combined a love of computer games, his knowledge of physiology, and his training in special education to assist children with disabilities in navigating their environments. For the many children who are carried or pushed in wheelchairs instead of being allowed to go for something on their own, virtual reality worlds create tremendous opportunity for exploration and learning.

High tech is improving the lives of everyday people. It's no longer reserved for outer space.

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Inman started developing his virtual reality programs for children in 1994, beginning with six children with cerebral palsy who used wheelchairs to get around. The children who completed the virtual reality study learned to approach or retreat from displays in the simulated world. They learned to go around virtual obstacles and, in general, improved their ability to drive their wheelchairs. They began to experience the sense of taking charge and the joy of personal discovery. When Inman saw the benefits of practice in virtual reality for these children, he began to consider the challenges of navigating without vision.

A grant from the U.S. Department of Education has enabled Inman and his colleagues to collaborate with the Oregon State Department of Education and the Oregon School for the Blind to develop innovative tools that can improve the education of children with disabilities. Kevin and Bryan, who are older, sharpened their listening skills the traditional way, out on the street, accompanied by an orientation and mobility specialist. Kendra, who is only 13, however, will be able to use Inman's programs to learn the skills Kevin and Bryan already have. "I'm going to ask lots of questions," she tells technology specialist Bob Disher with a shy smile, "because I've never done this before."

Key Practices

Virtual Reality Programs

Improve orientation and mobility skills

Develop a wider range of skills in less time

Increase initiative

"This is just a baseball cap," he says, placing it in her hands so she can "see" it along with the sensor device attached to the back. She puts on the cap and the earphones and is ready. She works the joystick to back away from a virtual highway where virtual cars speed by. "Now, move closer to it," Disher says and she does. "Can you turn so the cars are coming from behind you?" he asks. In 20 minutes with the program, she becomes more skilled at positioning herself at the side of the road, getting herself perpendicular to the sounds.

Using another program, Kendra turns her head to "watch" a horse gallop and whinny. After that, she listens to the horse as she practices screening out competing sounds. In the real world, where traffic noise is complicated by noise from aircraft, lawnmowers and rain, staying focused on specific sounds is essential. Kendra is excited. "I feel [the sound] in my forehead," she says, "when it's right in front of me." Of course, she will also practice in the real world accompanied by a real person. "This tool is not a substitute for being out in the community," Disher says.

However, the training that is done in real-world situations—on sidewalks and across intersections—is time consuming and sometimes risky. It's also limited to the number of environments available to the student and to the orientation and mobility training specialist. Success takes a long time. Being able to practice in the safety of the classroom will save many hours of intense training.

This kind of technology used to be reserved for airline pilots and astronauts who practiced hours of simulated flying before entering the cockpit. Now, the same wonderful technology is available to the child next door. Seated at her computer, she can call up a city street or the entire solar system. She can start out easy and then complicate the features of the environment. In addition to ease and safety, the sound card for these programs can be installed in most PCs for $300 to $500. Virtual reality is no longer too costly for any classroom.

National Geographic, The New York Times, NBC's Nightly News with Tom Brokaw, ABC's World News Tonight with Peter Jennings, and PBS television have covered Inman's innovations. "I'm normally a reclusive person," Inman says with a smile, "but I've come to appreciate what publicity can do to further a cause." He knows it can do a lot to change public opinion. Not only do parents of disabled kids see greater potential for their children, but people in general see these children doing amazing things. "This work can't help but result in more tolerance and more appreciation of diversity," he adds. Also, he's in favor of letting people know that high tech is improving the lives of everyday people. It's no longer reserved for outer space. "The U.S. Department of Education deserves a lot of credit," he says. "They invest in real people, in an effort to improve their public school education. This is especially important for children with severe disabilities."

Always looking for new challenges, Inman is presently developing programs that will help children who are blind and also have limited hearing. He points out that most people who are called "deaf" usually have some degree of residual hearing, and those who are blind have an amazing ability to use what hearing they have. "People with disabilities are extremely capable if they are given the chance to learn the skills they need to function in our modern society," he says.

The students using Inman's program at the Oregon School for the Blind are having fun. Kevin is back at the computer and has put on the earphones and the simulation cap. "Oh no, there's a goose honking too," he says. "Keep listening for the cricket," Disher says. "Can you tell I'm moving it close to the water?" "That cricket has gone down the drain!" Kevin says. There is laughter and applause. Virtually speaking, he's right!

Imagine standing at a busy intersection with eyes closed. Now imagine having to cross that intersection. Wish you could have had some virtual practice?

Dean Inman, Ph. D., University of Oregon, Eugene, OR

Communication: Let's Talk Behavior

"If only he could talk!" said Michael's mother, expressing her helplessness over her son's apparent frustration. Michael, who is deaf-blind, was screaming and biting his hand while his teacher tried to get him to participate in schoolwork. "If only he could just tell us what he wants, what's bothering him!"

We have all witnessed children acting out. Junior throws a tantrum in the grocery store when you say no to the gumballs. Katie screeches when you are on the phone. Most of us would agree that behavior has communication value. For children with disabilities, especially those with significant communication difficulties, behavior can be an incredibly effective means of expression. But when behaviors become difficult (e.g., tantrums, aggressiveness, self-injury), both children and families may be at risk.

V. Mark Durand, a researcher and associate dean of the College of Arts and Sciences at the University at Albany, State University of New York, has been working on a project designed to determine what Michael, as well as 23 other students with deaf-blindness, are communicating when they exhibit problem behaviors. His observations of special education classrooms over the years led him to believe that much of what is viewed as problem behavior is really an attempt to communicate a desire, a need or a frustration. He felt that if the message a child is trying to communicate through problem behavior could be identified, then it might be possible to teach the child to use more appropriate methods of asking for what he or she wanted.

Key Practices

The challenge, especially with children who have limited communication skills, is to figure out exactly what he or she is trying to communicate. With many children, once things have calmed down, it is possible to talk about what's going on. However, with a child who's developmentally disabled or who does not have good verbal skills, it seems that all we can do is guess.

Perhaps the child having a tantrum in the store means, "I've been good; I deserve that gumball." But maybe it's more like, "When we're in the store, you always stop listening to me." Or, "When I'm in the store, I feel starved." The possibilities for guesses are endless. Ten years ago, Durand developed a method for determining the communicative intent of behavior. Called the Motivation Assessment Scale (MAS), it consists of 16 questions that help a parent or teacher consider all possibilities and causes of behavior and select what is the most likely cause. "In just five minutes of using the scale," Durand says, "people begin to think differently. They go from 'He's just being bad,' to 'There's a reason for this behavior.'" This scale has proven so useful, it has been translated into 15 different languages and is used all over the world. "It's replaced the old ways of manipulating things in the environment and then watching the child react," Durand explains. "For example, if I ignored you and the behavior got worse, we could assume the problem was the result of feeling ignored. But testing that way can often work to increase the problem."

The MAS helps teachers and parents figure out where, when, and under what conditions problem behaviors occur. These are the clues for determining why the behavior occurs. Is the child misbehaving because he or she needs more sensory stimulation? To escape certain demands? To gain attention? To get something tangible, like a toy or food? Once they know the purpose of the behavior they can decide how to respond. They can then teach the child to use more acceptable behaviors that serve the same purpose.

For children with **disabilities**, especially those with **significant** communication difficulties, behavior can be an incredibly **effective** means of expression.

Michael's assessment suggested that his screaming and hand biting occurred when expectations were placed on him to work on classroom tasks that he disliked. If he got upset, bit his hand and screamed when he did not like the work, the teacher might end work earlier than usual. One way to possibly stop his outbursts would be to stop giving him challenging work. But that approach would thwart his educational goals. Instead of removing or eliminating activities and circumstances that seem to trigger difficult behavior, Durand's project, using "functional communication training," worked to teach Michael and the other students how to handle these situations by learning other ways to communicate their needs.

Previous functional communication training methods were designed for children with verbal skills or sign language ability. Different strategies and techniques are needed when using functional communication training with children whose speech is difficult to understand or who are non-verbal. One method is to teach the child

to use a vocal output device that emits clear, spoken words when activated. The vocal output communication devices can be programmed to play specific messages. Listeners don't need special training to understand the message. Even children with severe physical disabilities can use them and get the attention of a listener even if the listener isn't looking directly at him or her. "We work a long time to get the words right," Durand says, "so they will have the right effect." For example, the phrase, "Teacher, come here," may get old after the teacher has heard it a few times. "Could you help me?" has a nicer sound and serves the same purpose.

Training for Michael began by having him work on difficult tasks. Before he had time to get upset, his hand was placed where he could easily press the vocal output device that was programmed to say, "Help me!" He was then given assistance to make the task easier for him. Although he could not hear the voice output, it soon became clear to him that if he pressed the button on the device, he received the desired help on the task, making the task easier. Over the course of a few weeks, he began to use the device each time tasks were too difficult for him. Over time his behavior problems were significantly reduced. "Our work is different from what many researchers are doing," Durand says. "Others are looking at ways to change the environment, removing obstacles. We are more concerned with teaching the child skills for making a way in the real world, the world as it is."

Durand's research extends into other areas as well. As a professor of psychology, he has studied sleep patterns and behavior and is interested in investigating non-medical remedies for sleep terrors. He has also looked at the effects of music and odors on moods. His latest research investigates those factors that prevent kids with behavior problems from developing more severe problems.

Durand's research flows from those initial feelings of concern for children who showed problem behavior. "Why on earth would a child deliberately hurt himself?" he asked many years ago. His research has led to real answers, real ways to make things better for these children. "We know we're on the right track," he says, "when we see a child become more attentive, more interested in his work. But mainly," he adds, "when we see a smile. Having a better way to communicate makes a child smile."

V. Mark Durand, Ph.D., State University of New York at Albany, Albany, NY

Self-Determination: Charting Your Own Future

We each make decisions every day. We choose what to eat, what to wear, where to live or go to school, a career, who we marry. Our choices, big and small, determine the quality of our lives. Educators are finding that power over life choices is critical for people with disabilities.

Last fall, Andrew Prouty entered Minnesota's Hennepin Technical College with 120 other special education students. Of those, 30 are deaf, and eight, including Andrew, are deaf-blind. "College is my first step," the 19-year-old says. "My second step is finding a new job, and maybe I'll live in an apartment. If I get enough money, I could buy a house." Andrew obviously has dreams. He's willing to talk about them, and he's taking action to achieve them.

Brian Abery, project director and teacher at the University of Minnesota Institute on Community Integration, is fascinated by young people like Andrew. He wants to see more of them chart their life courses and determine their own futures. "As self-determination skills go up," he says, "so does self-esteem. Making decisions about—and having control over—the parts of life we think are important will result in the kind of life in which we continue to learn, take responsibility for decisions, and participate in the greater community."

Key Practices:

For years, Abery has been interested in family dynamics. "Parents generally make good decisions for their kids," he says, "but over time, they may, inadvertently, deprive their young adult of practice in decision making. As a result, some young adults never learn to take responsibility for and learn from their mistakes."

In his work at the Institute, Abery has found that people with disabilities can take charge of their lives and be leaders; they are often able to bring about amazing changes for themselves and for others. A 1995 newsletter published by the Institute contains a piece by Barb Eaton, a former resident of the state institution. Her video, "The Lost Years," recounts the story of her years in the institution. Telling her story pushed her to do things she had never done before, she says. She went on to help others tell their stories.

Inspired by young people like Barb Eaton and spurred by his work with other young adults with disabilities, Abery has developed materials to support and promote self-determination in young people who are deaf-blind. "It's essential," Abery says, "for these young adults to fully participate in their school, their work, and their communities. By doing so, they'll get to practice and refine those capabilities that will support them in becoming self-determined adults." Self-determination is naturally interwoven with a wide variety of other important outcomes, especially with increased feelings of self-worth and self-confidence.

Andrew says he was inspired to do more by his parents and his intervenor. "And from taking karate," he adds. His mother says he's benefited from what teachers and service providers have learned in Abery's programs. In addition, he took part in a self-determination seminar jointly developed and run by the National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind and the University of Minnesota at the American Association for the Deaf-Blind conference last summer. "Did he make his own decisions about what to do after public school?" we ask Andrew's mother. "Absolutely," she responds. "He is at the helm."

Abery believes that three components provide fertile ground for growing self-determination: the classroom, the student and the family. To encourage self-determination, classroom teachers need to insure that students exercise some control over their environment. Abery's in-service training programs help teachers do this. "It's important to focus on what the student CAN do," Abery tells the teachers, "rather than focusing on limitations. We need to help the student articulate their dreams so we can see the bigger picture."

Students also need opportunities to take responsibility, to be in the community and to be exposed to role models. The 20-module curriculum that Andrew will take at HTC this year will help him acquire skills that support enhanced self-determination. He'll practice job skills in role-playing activities and participate in simulated community experiences. He'll go out into the community to observe others at work. In addition, Andrew will be exposed to speakers who are deaf-blind—people who are making it in the outside world. This is a priceless opportunity for young people who are often geographically isolated from others like themselves.

The student's family constitutes the third piece. "Young adults kept telling us," Abery says, "how important it was that Mom and Dad understand and support their ideas." All parents struggle with how much power to give their children, but parents who have children with disabilities especially want to protect them. "I wanted to jump in and save him," Andrew's mother confides. "But I realized he had to make mistakes to learn. He needs to meet life head on and be responsible for himself and his decisions. It's been a long, hard road for us, wanting to protect him."

Abery's programs also teach families about person-centered planning, a process that facilitates listening, enables the exploration of dreams and beliefs, and results in a plan for making dreams come true. In this kind of planning, families begin to think in terms of the young adult's capabilities. They learn how to build on their child's strengths and gifts. Andrew's mother understands her son's goals. She is clear about her dreams for him. "We want to see Andrew happy with his life," she says. "We'd like to see him confident, wanting to continually learn, to help others, and to feel like a contributing member of society."

"Progress is made in small steps," Abery notes. "It starts out as simply as including the child in plans for a family vacation. It involves giving opportunities for real communication. Most of all, it involves listening, really listening, to the child's preferences. Of course," he warns, "as the child gains confidence, he or she will naturally want to exercise greater personal control."

His programs try to prepare parents and teachers for new behavior that may initially be viewed by some as difficult or insolent, but in reality, is typically a result of young adults with disabilities attempting to stretch their wings in almost exactly the same manner as their peers without disabilities. "We help them see it's a step in the right direction," he says.

Brian Abery, Ph.D., University of Minnesota, Minneapolis, MN

Self-determination is naturally interwoven with a wide variety of other important outcomes, especially with increased feelings of self-worth and self-confidence

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On the Cover

"Walls of Ice"

Mixed Media

Jared Marcus Diaz is a visually impaired student who is fully included at Centennial High School in Pueblo, Colorado. He is 17 years old. He feels that art improves his ability as an individual to communicate on multiple levels. Jared also feels that art promotes his ability to solve problems and gives him a sense of pride and belonging.

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